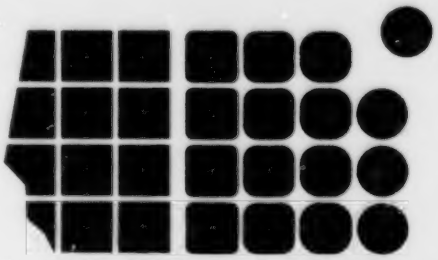

THE PREMIER'S COUNCIL
ON THE STATUS OF PERSONS WITH DISABILITIES

TOWARDS A NEW VISION OF ABILITIES IN ALBERTA

JUNE 1989

PREFACE

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An extensive consultative and planning process was symbolically initiated at a March 1987 meeting between Rick Hansen ("Man in Motion") and Premier Don Getty. It was after this meeting that the Premier set in motion the establishment of the Premier's Council on the Status of Persons With Disabilities to demonstrate the Alberta Government's commitment to the full and equal participation of all Albertans with disabilities in Alberta society.

A Steering Committee was struck in September of 1987 to manage the development of a proposal leading to the establishment of the Premier's Council. An intensive information gathering process was undertaken by the Steering Committee to ensure that individual consumers, their families, consumer groups, related professionals, as well as agency and government representatives from across the province had input into the Committee's recommendations. Following the submission of the Steering Committee Proposal and its acceptance by the Government, Gary McPherson was appointed as Chairman of the Council. Nominations for Council were requested and with the appointment of twelve Council Members in October 1988, the start-up challenges of the Premier's Council had been met.

The remaining challenges are much more complex. The Albertans which the Premier's Council serves are living in a province confronting rapid change: economic restructuring and the move towards a predominately urban society have broad implications for issues ranging from the availability of labour to the nature of health care. As well, many Alberta families no longer fit the historical two-parent model. Thus, the province is undergoing fundamental social change and such fundamental changes are necessitating extensive public policy review.

In addition to a dynamic context, the Premier's Council faces the challenge of addressing the rights and needs of an extremely diverse group of consumers. The Premier's Council is mandated to serve the interests of all Albertans with disabilities. The varying nature and breadth of these needs are not always understood by the public, the professionals, and the private and public agencies that serve persons with disabilities, or by disabled persons themselves.

The possibility now exists to establish Alberta as a Province leading the way in policy affecting persons with disabilities. The Council's opportunity lies in catalyzing comprehensive, integrative policy review to achieve this social change, however, the Premier's Council must proceed with this task in a consultative manner, ensuring its views reflect the interests

of all Albertans with disabilities. It must also pursue a clearly focused vision, avoiding duplications with existing initiatives and channelling its limited resources as effectively as possible.

The intent of this paper is to target the role for the Premier's Council on the Status of Persons with Disabilities; that is, **to outline the contextual challenges arising from our past and present, to paint a picture of our potential future, and to define the Council's role in leading this transformational change.**

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OVERVIEW

"Towards a New Vision of Abilities in Alberta" is a challenge to persons with disabilities, their representative organizations, service providers and government to forge a partnership and endorse a shared vision that will enable a transformation of public attitudes and public policies to occur in Alberta. This transformational change will result in the realization of "equal status" for all persons with disabilities in this province.

The paper addresses three key areas:

1. Transformation of Public Attitudes and Public Policy

In order to elevate the status of persons with disabilities to one of equality, a shift in focus must occur:

- from the limitation to the person
- from the disability to the ability
- from charity and pity to individual right and responsibility
- from a concept of costs to one of investment
- from institutional living to community living

2. A New Policy Framework

Future policy related to persons with disabilities must encompass three facets:

- Social perspective - a commitment to a dignified and humane society ensuring quality of life for all Albertans
- Economic perspective - a recognition of the significant economic and social contributions to be made by many persons with disabilities, and that support and assistance are an investment in the individual, regardless of the nature or size of the return on that investment.
- Citizenship or Individual Rights perspective - a commitment to equality for all Albertans

3. Principles to Guide Policy Development and Public Education

The Council believes that, if it is to accept the challenge of improving the status of persons with disabilities, it must propose a belief system which government, organizations and individuals can all accept and which will guide public education and policy development in the foreseeable future.

Cross Disability Perspective

The mandate of the Premier's Council is to work toward full participation of all persons with disabilities in the life of Alberta. Within this paper, reference to persons with disabilities is intended to include all those with physical and mental impairments (including learning disabilities), mental illness, hearing and visual impairments, and brain injury, whether the disability is visible or not.

A NEW ERA APPROACHES FOR ALBERTANS WITH DISABILITIES

Public Policy has Reflected Paternalistic Assumptions

Historically across North America, the definition of disability has been heavily influenced by medical etiology. Disabilities have been viewed through the perspective of discrete diagnostic categories; the symptoms and consequence of the diagnosis were the associated mental and physical limitations. This focus on illness traditionally has served to cultivate the belief that persons with disabilities are not "normal", not "able", and not "well". Solving the problem of disability meant "fixing" the person with disability. Those individuals who could not be "fixed" were assumed to be incapable. This assumption essentially applied, regardless of the nature of the disability.

Public (government) policy has traditionally reflected the limiting assumptions of this medical definition of disability. As a result, public policy has been paternalistic in its approach to persons with disability. Emphasis was placed on "curing" the person with disability but, in the absence of a cure, the alternative was protecting and caring for persons with disabilities. As a consequence, they were removed from their families and home communities and placed in institutions. Across North America, such segregation became the policy norm.

Public Policy has Historically Perpetuated Negative Values and Attitudes

This paternalistic policy approach by government has served to reinforce negative values and attitudes towards persons with disabilities. Albertans with disabilities from across the Province have been congregated in institutions such as hospitals, extended care facilities and nursing homes, most of which have a medical/custodial care atmosphere. This was done in the belief that it was best for all concerned.

Consequently, most non-disabled Albertans have lived their lives experiencing minimal contact with persons with disabilities. Moreover, such segregation has served to perpetuate the myth that not only must persons with disabilities be protected from society, society must also be protected from persons with disabilities.

The responses of private citizens to disability have mirrored these assumptions about limitations and incapability. Many fund raisers have mounted financially successful campaigns which portray persons with disabilities as objects of pity and charity and these images have reinforced beliefs in the helpless "plight" of persons with disabilities.

Our language has also reflected our mental images of charity and pity. Words and phrases such as "suffering from a handicap", "afflicted", "crippled", and "deformed" illustrate the inferiority assumptions in our descriptions of persons with disabilities. Language and humour also have represented negative attitudes toward persons with disabilities. Labels such as "spastic", "retard", "freak", and the "village idiot" have been used to depersonalize and devalue persons with disabilities. More recently, persons with disabilities pursuing independence and achievement have been described as "courageous", "heroic", and an "inspiration". Although these terms are more positive in tone, they again do not promote assumptions that persons with disabilities undertake "normal" activities. Segregation from society, congregation in institutions and language associated with disability have all served to perpetuate ignorance and fear in members of society as to the actual needs, desires, and capabilities of persons with disabilities.

Public Policy and Public Attitudes are now Reflecting Positive Changes

Public policy and public attitudes have become more enlightened in the last two decades. The American civil rights movements of the 1960's served to raise the consciousness of North Americans about the human rights of all citizens and new philosophies of treatment have demonstrated that community integration can be an effective alternative to institutionalization. Public officials, professionals, and service agencies are increasingly recognizing the importance of community support systems to promote healthy families and healthy communities.

The Charter of Rights has lead to increasing recognition of equality rights for all Canadians. This has been demonstrated by the recent Federal Court decision giving the right to vote to persons residing in institutional settings. As well, employment equity programs represent the growing public and private awareness of the right, the ability, and the desire of persons with disabilities to make a contribution to society. Finally, public figures such as Rick Hansen and his "Man-In-Motion Tour" have also educated the public to see the ability as opposed to the limitations in persons with disabilities.

The Future Holds Many Challenges

As we approach the 1990's, however, many challenges remain. Progress has undoubtedly been made in questioning our limiting assumptions about persons with disabilities, and public attitudes have become more enlightened. However, misunderstanding, fear, and negative judgments still exist regarding persons with disabilities.

Progress has often been slowed by ideological conflicts which have served to divide advocacy and consumer groups, with such groups often postulating opposing visions of lifestyle and service delivery. Such conflicts have contributed to pendulum-like swings in

approaches to service delivery, with programs often implemented in the absence of appropriate planning, funding and infrastructure. This is perhaps best illustrated by programs to discharge individuals from custodial care facilities without appropriate community and financial support services.

Public policy has been fragmented in its approach to persons with disabilities. Government agencies have often developed policy for specific segments of the population of persons with disabilities and this lack of integration has resulted in the promotion of a variety of approaches to policy and programs which often work at cross purposes to each other. Given such a fragmented approach, policy and service gaps or duplications exist for those persons who do not clearly fall into definite jurisdictional boundaries, e.g. people with brain injuries.

Community integration has also proven to be a complex issue. Under the present system, this lifestyle approach may not be viewed as appropriate nor be preferred by all people with disabilities because the support systems do not exist to give community living viability. **Individual choice and corresponding options are increasingly being demanded by consumers.** The long range goal of community integration can only be achieved by developing a responsive service system to support those options.

Finally, issues surrounding disability can only become more complex. For example, medical technology has led to the survival of many persons who may be left with severe impairments that are not well understood or accommodated by the existing service system. It is projected that the costs related to these often preventable disabilities will escalate dramatically in subsequent decades. Alberta's changing demographics will also be an influential factor. Our aging population can be expected to contribute to an increasing number of persons with disabilities. This trend will also have significant economic and social implications.

The Future Also Holds Promise

While the 1990's are expected to bring new challenges, they also hold new promise. As is recognized in "Caring and Responsibility: A Statement of Social Policy for Alberta", social policy and economic policy can no longer be developed in isolation. It states,

> "The future economic growth of the Province depends on the development of capable and productive individuals. Indeed, social policy must lead if Albertans are to fulfill their expectations. . .it must form the supporting factor in the development of a strong economic environment."

Such a perspective is positive for all Albertans who have a disability. This philosophy encourages the exploration of lifestyle and service delivery alternatives for persons with

disabilities given the Alberta Government's commitment:

> "to foster individual self-reliance and provide positive opportunities for individuals to achieve their personal goals, to take responsibility for their actions, and to be contributing and caring members of Alberta society."

The challenge for future economic growth in Alberta also necessitates more effective integration of policy in the public and private sectors. For example, as traditional entry-level labour pools continue to decline in numbers, Alberta employers are becoming increasingly open to exploring under-utilized labour pools. Coordinated public and private policy could effectively assist persons with disabilities in acquiring appropriate education, training, transportation and access to employment as well as necessary technical aids, benefits, and family/community support services.

Albertans with disabilities themselves, by their actions and example, continue to be effective public educators. Public attitudes are changing as Albertans increasingly gain opportunities for interaction with disabled persons. **As neighbours and co-workers come to know and work with individuals with disabilities, the focus of awareness will continue to shift to the person from the limitation, and to the ability from the disability.**

POLICY IN THE NEW ERA MUST BE INTEGRATED, ENABLING, AND PREVENTION FOCUSED

Public Policy towards Persons with Disabilities needs Transformation

A critical precursor to current and future public (government) policy revision is the definition of a **policy field of disability**. Such a policy field must be based on the premise that all policy with potential to affect persons with disabilities must contribute to and reinforce a consistent, comprehensive, and positive vision of persons with disabilities.

Future policy related to persons with disabilities must encompass three facets:

- **Social perspective** - a commitment to a dignified and humane society ensuring quality of life for all Albertans
- **Economic perspective** - a recognition of the abilities and potential of many people with disabilities to make a contribution to society
- **Citizenship or Individual Rights perspective** - a commitment to equality for all Albertans.

Government and private sector policy must also be integrated if this positive vision for persons with disabilities is to be achieved. Recruitment practices, job design, and disability benefits, are only a few examples of private sector policy decisions which need to be compatible with public policy if persons with disabilities or employees who become disabled are to be enabled for employment.

A final component of the transformation of both public and private sector policy must be the replacement of the concept of cost with the concept of investment. Given our historical paternalistic assumptions, we have viewed service delivery for persons with disabilities as necessitating ever-escalating financial expenditures because policies have fostered dependence and failed to recognize the potential payoff to society of supporting people in the mainstream. When policies and programs are designed to facilitate independence, refinement of ability, and self-reliance in individuals and families, then financial outlays can often be short-term in nature. And for those programs that are clearly long-term, expenditures can be minimized, becoming periodic in application as opposed to ongoing.

Public Values and Attitudes need Transformation

Transformation of public values and attitudes with regard to persons with disabilities is a mammoth and complex task, yet it is only through the awareness and re-education of all Albertans regarding existing limiting assumptions, values and beliefs that Albertans with disabilities can become full and equitable participants in Alberta society. Thus, there is a

need for complementary initiatives by government, the private and not-for-profit sectors, communities, and individuals to mobilize attitudinal change.

Fundamental to such educational initiatives must be a focus on ability and potential. We as Albertans must come to understand that persons with disabilities are not handicapped by their disability; rather, they are limited by inflexible social and physical environments which place the responsibility of adaptation on persons culturally defined as not "normal". Government policy that reflects positive, enabling values and attitudes towards persons with disabilities will have a strong influence on societal views.

Disability Policy must include a Focus on Prevention

In addition to defining a policy field of disability and promoting positive values and attitudes, public policy makers must recognize the interrelationship of lifestyle and the development of certain disabilities. This reality has been recognized in some cases; for example, education campaigns have been mounted to educate expectant mothers as to the detrimental affects of smoking and alcohol consumption on the development of the fetus. Much is left to be done, however. The occurrence of one of the most rapidly growing disabilities, i.e. brain injury, can be closely related to lifestyle choices of the high risk population of young adult males.

Thus, public policy must reflect an emphasis on the promotion of healthy individuals, healthy families, and healthy communities. The Premier's Commission on Future Health Care for Albertans has undertaken a commitment to develop policy that focuses on "innovation, promotion, and prevention". However, the responsibility for this promotion does not rest with public policy alone. The private and not-for-profit sectors, communities, families, and individual Albertans all have critical roles to play in the prevention of illness and injury and the promotion of health.

THE PREMIER'S COUNCIL FACES A CHALLENGE OF LEADERSHIP

The Premier's Council must Focus its Limited Resources

The challenge confronting the Premier's Council is immense and complex. Public expectations are high as consumers, advocacy groups, service agencies and government officials look to the Premier's Council to catalyze significant change. As a result, it is critical that the Premier's Council focus its resources on key priorities and produce visible results.

The Premier's Council also recognizes that it is only one of many players working to facilitate full and equal participation of Albertans with disabilities in Alberta society. In such an environment, cooperation and integration of initiatives serve to maximize the resources of all players, avoiding inefficiencies of duplication. Thus, **the Premier's Council does not see its role as one of competition with existing representational organizations nor does it see its role as a service provider.** Rather, the Premier's Council sees its role as that of a catalyst. It must use this opportunity to facilitate coalition and collaboration between consumers, advocates, government departments, and private and not-for-profit sectors to mobilize change.

The Premier's Council must Lead in Policy Development

Given its cross-disability vantage point, the Premier's Council can play a critical role in identifying immediate and long-term priorities for policy review and development. These priorities include the following:

1) the need for the definition of a public policy field of disability to ensure a cross-disability perspective and consistency in all policy affecting Albertans with disabilities;

2) the need to ensure that existing and future public policy impacting persons with disabilities is developed in a comprehensive and integrated manner;

3) the need for long-term change agentry to ensure that public sector programs and services consistently promote positive social roles for Albertans with disabilities;

4) the need for integration of public, private and not-for-profit policy to mirror these policy principles.

The Premier's Council must Lead in Public Education

Public education continues to be a priority activity through which the most significant obstacles to Albertans with disabilities can be removed. In order to complement the initiatives undertaken by other organizations in this area, the Premier's Council's resources and energies are best channelled in the following areas:

1) the need to address a spectrum of deep-seated cultural beliefs which contribute to fear, limiting assumptions, and misunderstandings regarding individuals with disabilities. Initiatives would focus on the capability and potential of persons with disabilities to fulfill positive social roles;

2) the need to integrate public education with public policy so that the impetus for transformational change is accelerated.

The Premier's Council must Represent Its Constituents

The process that will be employed throughout the mandate of Council will place a heavy emphasis on consultation as a means of information gathering and validation.

Consumers and their families must be viewed as the primary "experts" in the direction that public education and policy development initiatives should take in elevating the status of disabled persons. As such, consultation with consumers will become an integral part of policy development and revision in this Province.

THE COUNCIL'S MISSION

The Council's Mission Statement is as follows:

"TO ENHANCE AND PROMOTE THE OPPORTUNITY FOR FULL AND EQUAL PARTICIPATION OF PERSONS WITH DISABILITIES IN THE LIFE OF THE PROVINCE."

This Mission Statement is extracted directly from the Premier's Council on the Status of Persons With Disabilities Act.

THE COUNCIL'S PRINCIPLES

To focus pursuit of the mission, five principles have been proposed. These principles form the belief system that will guide Council's input into the two key areas of policy review and public education. These principles are interrelated and each must be viewed in the context of the others.

EQUAL STATUS, PERSONAL CONTRIBUTION AND INHERENT WORTH

- Persons with disabilities must be recognized for their abilities and equal status and, therefore, any support is viewed as a means to enhance their abilities and to recognize their equal status as citizens.
- The concept of return on the investment must include the economic contribution people will make in terms of taxes and dollars reinvested in the community, community service, societal enrichment and enhanced quality of life.
- Public education and policy discussion must encompass and create an awareness of the interrelationships of social, economic, and human rights issues.

EQUITY OF OPPORTUNITY

- Barriers to participation in society that are purely a function of disability must be removed in order to create an equal playing field. Among the barriers are lack of public awareness, lack of flexible and available supports, and financial costs directly related to the disability.
- The impact of additional costs related to special conditions incurred directly as a result of a disability must be substantially reduced or eliminated.

INDIVIDUAL RESPONSIBILITY AND PERSONAL CONTROL

- A system is needed that ensures individuals have the right and the opportunity to make informed decisions and choices about issues affecting their lives.
- Mechanisms to support and assist individuals to make decisions must exist and must be provided in a way that will maximize freedom of individual choice, without denying the necessity to intervene where those decisions would clearly result in purposeful self-destruction or harm to others.

- Personal and financial supports must be in place for those who need them so that genuine options exist from which to choose.
- Freedom of choice encompasses the concept of dignity of risk and includes the implications/consequences of risk taking. A disability does not relieve individuals of responsibility for their own lives and their obligations as citizens.

OPPORTUNITY FOR FULL PARTICIPATION IN COMMUNITY LIFE

- Individuals with disabilities must have a range of options for living and working in the community that provides opportunities to maximize participation in the life of the community of his or her choice.
- Support systems must be in place to facilitate each individual's efforts to reach their full potential.

CONSUMERS AS CONSULTANTS

- Consumers and their families/advocates must have input into policies that have potential to affect the status of persons with disabilities.
- Consultation with consumers must occur as a matter of course.

CONCLUSION

A unique opportunity exists in this Province to fundamentally change the lives of persons with disabilities. The Premier's Council can play an instrumental role in catalyzing that change. To be an effective agent of change, the Premier's Council must focus its limited resources on the most strategic targets. Those targets are primarily in the area of public policy and public education. Public policy can be amended and public values and attitudes can be adjusted. It is through pursuit of these changes that the Premier's Council on the Status of Persons with Disabilities will play its role in achieving a "Vision of Abilities in Alberta".

The Action Plan for achieving this new vision can only be mapped out when the vision itself, and the principles on which it is based, have received widespread endorsement. Upon this foundation of support, the Council is building a plan to achieve its mission.